

U.S. Public Health Service
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
(NCBDDD)

Records of the Meeting of the
National Task Force on
Fetal Alcohol Syndrome and Fetal Alcohol Effect

September 20-21, 2002

Held at the
Marriott Marquis Hotel
Atlanta, Georgia

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Meeting Summary

At the September 20-21, 2002, meeting of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, the Task Force was joined by liaisons from state health departments, academia, and other organizations such as the National Organization of Fetal Alcohol Syndrome (NOFAS), the Center for Science in the Public Interest, the American College of Obstetrics and Gynecology (ACOG), the American Academy of Family Practitioners (AAFP) and the American Academy of Pediatrics (AAP).

Reports from the Scientific Working Group subgroups were made to the Task Force. These included reports from the Screening and Diagnosis of FAS Subgroup, the Essential Services for Children with FAS and ARND Subgroup, the Screening and Diagnosis of ARND Subgroup, and the Screening and Intervening in Prenatal Alcohol Use Subgroup. Other presentations included a report on the SAMHSA/CSAP stakeholders meetings and town hall meetings, agency updates by NIAAA and CDC, a report on the key concerns of biological mothers of children with FAS, and a presentation on Health Canada's FAS activities.

NCBDDD director Dr. José Cordero agreed to follow up on a question as to the likelihood that the recommendations of the Surgeon General's Conference on Mental Health Services, many of which are applicable to FAS, will be implemented by the Secretary. Dr. Cordero will continue to support implementation of the Surgeon General's recommendations on access to health care and will brief the Task Force on the entire report in the coming months.

Dr. Floyd provided the Task Force with an overview of the newly created Scientific Working Group on Diagnostic Guidelines for FAS and ARND. Subgroups from this Working Group will present their preliminary recommendations to the Task Force at this meeting. The following **screening and diagnostic criteria** were presented by the chairs of the Screening and Diagnosis of FAS Subgroup, Drs. Riley and Jones, for the Task Force's consideration:

If the child has all three characteristic facial features – whether alcohol exposure is known or unknown – then the child should be referred for appropriate FAS evaluation and diagnostic testing.

If prenatal alcohol exposure* is known, then:

- C The primary health care provider should document this exposure and closely monitor and follow the child's growth and development.
- C If any one of the three characteristic facial features are present, AND abnormalities in growth and/or development are present (as defined below), then the child should be referred appropriately for FAS evaluation and diagnostic testing. Depending on the community, such referrals might

be made to a developmental pediatrician, FAS clinic, genetics clinic, or other specialty provider.

* Heavy drinking is defined as 7 or more drinks per week or binge drinking (4 or more drinks on an occasion).

Positive FAS Screening Criteria

Evaluation is needed to produce such evidence, but that has not been funded. This is part of a circular pattern in which research produces the evidence and increases the practice, which then provides more data for the evidence. The criteria developed by the workgroup were:

- Face: Based on racial norms, individual exhibits one or more characteristic facial features:
 - < smooth philtrum
 - < thin vermillion
 - < short palpebral fissure \leq ? percentile
- Growth: Prenatal or postnatal height and/or weight \leq 10th percentile (adjusted for gestational age based on AAP standards) [adjusted for parental stature? For race/ethnicity?], documented at any one point in time.
- Developmental/Behavioral: documented overall head circumference (OFC \leq 10th percentile), or reported neurobehavioral problems, mental deficiency, poor attention span, fine motor problems, social-emotional problems, etc., with or without mental retardation.

Diagnostic Criteria for Individuals with FAS

A positive diagnosis requires a positive for each of the four categories.

[May not require a history of alcohol exposure if other criteria are met]

- Face: Based on racial norms, child exhibits all three characteristic facial features:
 - " smooth philtrum
 - " thin vermillion
 - " palpebral fissure \leq ? percentile [question 10th or 2.5th – work group will seek data to drive decision]
- Growth: Confirmed prenatal or postnatal height and/or weight [question about height for weight] \leq 10th percentile; work group will seek data to drive decision] (adjusted for gestational age up to age two, consistent on AAP standards).

Task Force input included recommended additions to the screening guidance:

C The insertion of a footnote indicating that children with FAS *and* mental

- retardation are in the minority was recommended.
- C Insert "known or suspected due to other substance abuse" in the educational material accompanying the guidelines.
- C Have other literature to inform people that the presence of three FAS features might indicate exposure.
- C Add special guidelines to address the evaluation of adopted or foster children.
- C Change "child" to "individual" and take out the age range.

Suggested additions to the diagnostic criteria include:

- C Again, to reduce the ingrained clinical association of FAS with the leading cause of mental retardation, add "with or without mental retardation" to the other signs of FAS (e.g., obvious structural brain abnormalities, and/or confirmed neurodevelopmental or neurobehavioral disorders, etc.)
- C Do not tie a definition to a technology, the use of which is variable, but educational materials can discuss it.

Other Feedback to Screening and Diagnosis of FAS Subgroup:

- C It could be a Task Force recommendation to the Workgroup to drop the diagnostic condition requiring history of alcohol exposure if other criteria are met.
- C Racially normed guides, with a standard deviation of 2.5, were strongly recommended
- C Perhaps the Subgroup should acknowledge that FAS is an identifiable disorder and clarify that these criteria are for FAS. However, there is a spectrum of disorders associated with prenatal alcohol exposure and the terminology for these has not been clearly delineated. Some refer to this spectrum of disorders as FASD.

Deborah Cohen and Kathleen Mitchell reported on the work of the *Essential Services for Children with FAS and ARND Subgroup*. A chart of services essential for both the affected child and family across the lifespan was presented. The group adopted a holistic approach. That is, services should be family-centered and must be adapted based on the developmental stage of the child and the needs of the family. Since it is unlikely that states will have resources to develop FAS-specific services, it was felt preferable to make the service system accessible and responsive to a child with FAS. Dr. Cohen highlighted the services and needs identified by the Subgroup.

- C The Subgroup recommended a presence in every state to ensure that the systems serving children and families receive materials and education on FAS. The Task Force agreed that this kind of open-system coordination be developed and funded, without over-specificity as to how that would be done in each state.
- C There is a need to gear mental health services to those with FAS, both out-patient and in-patient. A DSM code is needed to allow psychiatry to be reimbursed without having to identify another diagnosis.
- C Other services were identified to add to the workgroup's list. It was recommended; however, to prioritize the services specific to children/families

- with FAS/ARND as opposed to those common to all children/families.
- C Even without evidence on specific interventions, assurance is needed that children with FAS and other prenatal alcohol-related conditions receive the basic services that any child needs, because if not seen by a provider at some point identification of their FAS and access to an expert diminishes.
 - C Details about existing state programs/services are needed. Families and service providers need a profile of the entry points that the child will encounter as s/he develops. An important intervention point is among women who abuse substances.

Other Feedback to Essential Services for Children with FAS and ARND Subgroup:

- C The Task Force could advise that states identify the sites and the resources needed to ensure that appropriate mental health services exist for those with FAS (e.g., through responsive legislation), and that the Workgroup follow up on that line of inquiry.
- C To increase the evidence base for effective interventions, the Subgroup should consult the CDC Epidemiology Program Office's (EPO) Division of Prevention Research and Analytic Methods (DPRAM) and the Task Force on Community Preventive Services, which investigates evidence-based interventions for inclusion in the Guide to Community Prevention Services.
- C The Subgroup should identify the services that need to be offered and evaluated, at least on a demonstration basis, as well as identify a selection of seemingly effective services.
- C A suggestion was made to include a preamble to the Essential Services recommendations that provides a philosophy about a range of needs for children with disabilities (care, home support, etc), and then list the specifics. These should be parallel those cited in the Individuals with Disabilities Education Act (IDEA) to make the issues clear to policy makers.
- C A list of the professional groups trained in CSAP FAS trainings will be provided to those interested (Dan Dubovsky).
- C Information will be provided on South Dakota's 2-day workshops on FAS (Charles Schad).
- C To nurture field experiences, the Task Force should identify promising approaches in the diagnosis/treatment of individuals and their families, support those by providing funding/expertise, and evaluate those likely to be disseminated to the field. A sustained e-mail conversation about how the Task Force could recommend a procedure to do environmental or pilot projects with less than the usual scientific rigor, while still ensuring that the money is well spent, was suggested.

The *Screening and Diagnosis of ARND Subgroup* noted that first the issues of screening and diagnosing FAS have to be resolved before progress can be made on Alcohol-Related Neurodevelopmental Disorders (ARND), or other prenatal alcohol-related conditions.

Every assessment to date indicates that ARND is more common than FAS. The workgroup defined ARND and specified FAS as a starting point for fully defining the nature of ARND deficits. They called for a meeting on ARND to include professionals from the different related fields to address the issues of ARND barriers and challenges, better terminology to reflect the current understanding of this disorder, and behavior-based guidelines. Identified research needs include exploration of the distinguishing features of ARND from similar disorders such as ADHD; development of the evidence base to delineate the full range of ARND dysfunction, especially across exposure levels; work on the influence/interrelationship of parental and social environments and organic damage; work on the global health impact of prenatal alcohol exposure; and investigation into ethnic variations in vulnerability to prenatal alcohol exposure. Longitudinal studies across the life span are essential.

In their initial meeting, the *Screening and Intervening in Prenatal Alcohol Use Subgroup* discussed the possible use of an at-risk strategy distinguishing between those at high and low risk. Current screening tests include the T-ACE and TWEAK tests, as well as the "4Ps" screening tool. The practitioner's advice is powerful; often, a brief intervention will be adequate, although extended interventions are also effective. For those at low risk (a low prevalence setting), all reproductive age women should be advised not to drink during pregnancy in order to ensure a healthier baby. Any suspicion of drinking would move a woman to the high-risk protocol, administering the T-ACE or TWEAK and interventions as needed.

An instrument to screen for heavy episodic drinking, which puts embryos at most risk, may be more efficient and provide more potentially useful research data. Similar to ACOG's recommendation for assessment of domestic violence once per year, any such recommendation needs to be clear that it is asked of all women. It should be integrated into other initiatives such as not smoking and folic acid.

Testimony from the **CSAP town hall meetings** will be given to Congress this month. It is hoped that a companion book to this report will help those parents trying to access services to prove that FAS exists and to support the complexity of the disability. Anger was expressed at these meetings that, with all the funding spent in the last 30 years, little has supported programs that encourage and mentor the families. One unfortunate gap at these meetings was the lack of birth mother attendance. A "Birth Mothers' Summit" is to be held in 2003. Next year, town hall meetings will be held in Mississippi, California, New York (Buffalo), Washington D.C., Arizona, and South Dakota. The needs identified by town hall meeting participants were outlined for the Task Force, as were CSAP's recommendations for the future. It was noted that these town hall meetings could also contribute to qualitative research on how to address some of these problems.

In discussion, priority needs were suggested for funding support, to provide training for all who might encounter persons with FAS; education on FAS core disabilities and extensive intervention training in each system; support for existing experienced family

networks; support for birth mothers, including training them as trainers in the chemical dependency field; and development of exemplary community systems of care and effective prevention programs, with treatment as a priority. It was also noted that training of health care professionals must begin with the inclusion of FAS questions on licensing exams.

The recommendations of Canada's national Fetal Alcohol Spectrum Disorder advisory committee were outlined. In Canada, FASD is an umbrella term. It is not a diagnostic term. It is used by clinicians for screening/referral, and cannot be used when it is known that the mother did not drink alcohol during pregnancy. Parameters for the use of the term outside of the medical/clinical community need to be developed. In the medical community, only people with the broader knowledge of FAS diagnostic terminology should use this term. The committee advised, along with Health Canada, the establishment of an expert panel to develop national standards for FAS diagnosis. This will occur on October 6, 2002 in Winnipeg.

The Canadian committee could identify no reliable screening tool currently in use with demonstrated validity (and specificity) to predict FAS. Screening cannot be equated with diagnosis. If the purpose of screening is to get these children to the diagnostic clinic, then there must be clinics and services available initially and at follow-up. Research needs were outlined, as were their next steps.

Public comment from individuals related their experiences and produced recommendations, including support for 1) a national mandate that each state have an FAS coordinator to coordinate services throughout the state and help families negotiate the system; 2) guaranteed funding for a diagnostic center in each state to facilitate early intervention; and 3) assurance that these two recommendations are effectively implemented through an annual meeting of state coordinators to facilitate cross-communication. In other comments, the Center for Science in the Public Interest agreed to draft a letter on behalf of the Task Force to support the CSPI's petition to the Treasury department to re-design alcoholic beverage warning labels. The CSPI representative also requested consideration of a Task Force recommendation of communication by the DHHS Secretary to the Treasury Secretary about this labeling issue. The Teratology Society on Fetal Alcohol Syndrome asked if the Task Force would endorse a statement on FAS which they hope to be broadly published.

Task Force Action Items:

- C The Center for Science in the Public Interest (CSPI) will draft a letter on behalf of the Task Force, which will be circulated to the Task Force members, to support the CSPI's petition to revise the design specifications for alcoholic beverage warning labels. The CSPI liaison to the Task Force also recommended communication by the DHHS Secretary to the Treasury Secretary about this labeling issue.
- C If consensus is reached (e.g., by e-mail) by the Task Force to endorse or co-author the Teratology Society's proposed guidelines statement, members

comments will be circulated and the resulting document will be sent out electronically.

- C The Task Force should request a meeting with the new Surgeon General, providing him information in advance, in order to outline the magnitude of the problem of FAS and to ask him to raise the issue in his talks around the country.
- C Dr. Ken Warren agreed to draft an update to the Surgeon General's warning on drinking during pregnancy. This would be circulated to the Task Force for their comments.

Discussion of Task Force Approaches:

- C The next meeting agenda should allocate time to review progress on previous action items and discuss potential recommendations, keeping the informational aspect of the meeting at a minimum.
- C New business will be conducted first, when energy is still high.
- C Time between meetings will be utilized, which requires the members' response to e-mails.
- C CDC was asked to send informational materials electronically prior to the meeting so that most of the agenda could focus on dialogue/discussion, and to provide PowerPoint presentations as text documents.
- C The DFO and Executive Secretary will list the recommendations that were officially endorsed, if any, and outline action items.

**Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect**

**Minutes of the Task Force Meeting
September 20-21, 2002**

SEPTEMBER 20, 2002

The Department of Health and Human Services (DHHS), Centers for Disease Control and Prevention (CDC), National Center for Birth Defects and Developmental Disabilities (NCBDDD), convened a meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) on September 20-21, 2002. The meeting was held at the Marriott Marquis hotel in Atlanta, Georgia.

The members present were:

CHAIR: Edward P. Riley, Ph.D., Director, Center for Behavioral Teratology, San Diego State University

EXECUTIVE SECRETARY: Dixie E. Snider, M.D., M.P.H., Assistant Surgeon General, Associate Director for Science, Centers for Disease Control and Prevention (CDC)

DESIGNATED FEDERAL OFFICIAL: Louise Floyd, D.S.N., R.N.

MEMBERS:

Michael E. Charness, M.D., Chief, Neurology Services, Harvard Medical School

Claire D. Coles, Ph.D., Director, FAS Center, Marcus Institute; Professor, Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine

Nancy L. Day, Ph.D., Professor of Psychiatry and Epidemiology, University of Pittsburgh

C. Jocie DeVries, Founder/Executive Director, FAS Family Resource Institute (FAS FRI)

Kathleen T. Mitchell, Program Director, National Organization on Fetal Alcohol Syndrome (NOFAS)

Luther K. Robinson, Jr., M.D., Associate Professor of Pediatrics, State University of New York at Buffalo

Charles M. Schad, Ed.D., Educator.

STANDING MEMBER: Faye B. Calhoun, D.P.A., M.S., Associate Director for Collaborative Research Activities, National Institute for Alcohol Abuse and Alcoholism

(NIAAA)

LIAISON REPRESENTATIVES :

Deborah E. Cohen, Ph.D., Director, Office for Prevention of Mental Retardation and Developmental Disabilities, New Jersey Department of Human Services

Christopher Cuniff, M.D., Professor of Pediatrics, University of Arizona

Karla Damus, R.N., Ph.D., Senior Research Associate, March of Dimes

George A. Hacker, J.D., Director, Alcohol Policies Project, Center for Science in the Public Interest (CSPI)

Robert J. Sokol, M.D., Director, Department of Obstetrics and Gynecology, C.S. Mott Center for Human Growth and Development, Wayne State University, American College of Obstetrics and Gynecology (ACOG)

Daniel C. Vinson, M.D., M.S.P.H., Professor, Department of Family and Community Medicine, University of Missouri-Columbia; American Academy of Family Practitioners (AAFP)

Members: Fred W. Garcia, and Theresa M. Maresca, M.D., were absent.

CDC staff attending over the course of the meeting were: Jacquelyn Bertrand, José Cordero, Connie Granoff, Karen Hymbaugh, Elizabeth Parra, Jorge Rosenthal, Tanya Sharpe, Jasjeet Sidhu, Jacqueline Vowell, Mary Kate Weber.

NIAAA staff present were: Deidra Roach, Kenneth Warren

Members of the public or presenters to the Task Force present over the course of the meeting were:

Susan Astley
Christine Barakat
Sara Horton Bobo
Julie Conry
Janine Denis Cook
Jocelyn Cook
Bob Demaree
Franklin Desposito
Renn Doyle
Dan Dubovsky
Laurie Foudin
Pam Gillen

Daniel Hyman
Kay Johnson
Ken Lyons Jones
Linda LaFever
Angelina Locklear-Taylor
Diane Malbin
Vicky McKinney
Colleen Morris
Marie J. Murray
Karen Stern
Marceil Ten Eyck
Ann Waller

Ann Wilson
Georgiana Wilton
Barbara Wybrecht

Rob Wybrecht
Ted Wybrecht

Opening Comments

The Task Force was convened by Chair Dr. Riley at 2:11 p.m., and Executive Secretary Dr. Dixie Snider welcomed the attendees. He welcomed the expertise of the new Liaison members, who represent the views of their sponsoring organizations and will help to disseminate the Task Force's recommendations. He looked forward to working with those present and with Tom Donaldson, the Executive Director of NOFAS. Mr. Donaldson was appointed, but could not attend this meeting.

Dr. José Cordero, director of the NCBDDD, greeted the Task Force in the course of its work. He reported having a meeting with the director of the new DHHS Office of Disability. The DHHS definition of disability is broad and includes mental retardation. He expressed appreciation of the Task Force's contribution to the Center's successful first year and progress in addressing disabilities and health. Dr. Snider also reported that DHHS has formed a Research Coordination Council, which reports to the Assistant Secretary for the Budget and, for the first time, brings the scientists into the budget process. One of Secretary Thompson's research themes for 2003 and beyond addresses disabilities.

Dr. Calhoun recalled CDC's co-sponsorship of the Surgeon General's Conference on Mental Health Services to include those with mental health disabilities. She asked the likelihood that the conference's recommendations, many of which were applicable to FAS, would be honored by the Secretary. Dr. Cordero will follow up on that question, and continue to support implementation of the Surgeon General's recommendations on access to health care. The Task Force will be briefed in the coming months.

Overview of the Scientific Working Group on Diagnostic Guidelines for FAS and ARND

Dr. Louise Floyd reported that in 2002, CDC received a Congressional mandate to develop diagnostic guidelines for FAS and other prenatal alcohol-related conditions, to incorporate the guidelines into curricula, to disseminate curricula, and to coordinate these efforts with the National Task Force on FAS/FAE and others. The Scientific Working Group on Diagnostic Guidelines for FAS and ARND was created and is charged with the development of the screening and diagnostic guidelines.

The Scientific Working Group's first meeting was held July 12, 2002. The key issues addressed at this first meeting were to: 1) identify the barriers to screening/diagnosis of FAS/ARND by primary care providers, 2) discuss the current tools to screen and diagnose these conditions, 3) determine what information is needed to improve screening and diagnosis, 4) demonstrate community-based approaches that lead to enhanced screening and diagnosis of children with FAS/ARND, and 5) determine the critical components of a guideline to assist primary care providers in screening and

diagnosis. Four subgroups were created to begin developing preliminary recommendations. These subgroups include: Screening and Diagnosis of FAS, Screening and Diagnosis of ARND, Essential Services for Children with FAS and ARND, and Screening and Intervening in Prenatal Alcohol Use. Subgroup Chairs will report their group's initial recommendations at the Task Force meeting today and will convene again as needed. The Subgroups on FAS screening and diagnosis and essential services for children met on the morning of September 20th for a second time.

Reports from the Scientific Workgroup on Diagnostic Guidelines for FAS and ARND

Screening and Diagnosis of FAS Subgroup Report

Drs. Riley and Jones reported on the deliberations of the Screening and Diagnosis of FAS Subgroup that occurred on the morning of September 20th. They presented the following screening and diagnostic criteria for FAS to the Task Force for consideration.

See the Meeting Summary Section of this report (page 1/7), for the proposed criteria.

Discussion included:

- C *Is the palpebral fissure the actual measurement or a ratio of the intercanthal distance to the palpebral fissure width?* It is the actual length of the palpebral fissure.
- C *When considering growth, was there any discussion about large children and their families, some of whom are so large, they never go below the standard chart?* That is a good point, but unresolvable. Growth charts are only differentiated by gender, not by ethnicity, parent-specific size, etc. For screening, these will have to suffice.
- C *Why require three characteristics for diagnosis; why not two as in screening?* Because cutting down, even by only one feature, greatly lessens sensitivity and specificity.
- C *Was there any discussion about screening for adults?* No; at the last meeting the subgroup discussed cutoff ages for infancy and toddlers to age 3. It is hard enough to define criteria for children, who have much more obvious symptoms than adults, and facial features change over time. There is no age limit on the diagnostic criteria and the issues of diagnosis are different, although the screening criteria remain the same.
- C *What is the argument for saying "upon known exposure" versus "highly suspected exposure"?* Many factors prevent knowing exposure for certain, such as denial or lack of access to alcohol history of the birth mother; but there still may be something in the chart that may suggest exposure. The screening criteria are designed to maximize sensitivity. It is also hoped that the guidelines, a work in progress, will change diagnostic practice.
- C *Ms. Locklear-Taylor agreed to the need for adult criteria, having only heard about FAS in a workshop where she learned that FAS was her adult son's problem. She had to engage a lawyer to present this as a mitigating circumstance to consider in the judgement of her son's case. One of the purposes of these guidelines is to*

educate and to ensure that people recognize FAS when they see it.

- C *Ann Streissguth's 1986 workgroup reported that in France they identify FAS without linking it to mental retardation. Have they identified an adolescent characteristic that could be useful in U.S. as well?* Streissguth published a study of the children initially diagnosed with FAS and followed them through adolescence, describing their facial changes. This and three other similar studies were done before the three key features were formally identified. Streissguth and two others identified the changes, which fit the definition of the development of a normal *infant* face. The three facial features can remain to maturity, but are less apparent. It is important to look for the full face of FAS at any age, when working with an adult population (e.g., from a childhood photo). Mental retardation is another feature even without the full range of FAS' IQ effects, but many physicians tie it to the FAS diagnosis.
 - C *Some physicians will not diagnose FAS if the child has a normal or high IQ. The problem lies with the use of the popular statement that "FAS is the leading cause of mental retardation," even though FAS children with mental retardation are in the minority.* While this is true, the subgroup wished to keep the guidelines as minimal as possible. A suggestion was made to insert a footnote indicating that FAS children are not always mentally retarded.
 - C *How would you handle the common occurrence of a mother's documented heavy alcohol use after delivery, even though none was documented prenatally?* Dr. Sokol reported that this was also discussed by the IOM report committee. FAS and ARND are very hard to diagnose. False positives are possible without strict criteria; the sensitivity/specificity need to be balanced to avoid over- or under-diagnosis. Having the face is a reasonable surrogate. *So if alcohol use is known or highly suspected due to other substance abuse, would it lower the specificity so much as to be problematic?* If there is no evidence of alcohol or substance abuse, the presence of the facial features still allow that to be addressed. Putting it in the guidelines risks confusion, but like smoking, one drug use is a strong predictor of other drug use. A suggestion was made to insert "known or suspected due to other substance abuse" in the guideline's educational material.
 - C A suggestion was offered to have literature that informs people that the presence of three FAS features might indicate an exposure. Mothers of children brought to an FAS clinic sometimes do not have documented alcohol exposure, although they report use of other drugs. One mother was so focused on halting her illicit drug use that she did not even consider her alcohol use as a problem.
 - C Add special guidelines to address the evaluation of adopted or foster children.
 - C *Was there any discussion of eliminating the face from the criteria?* Yes, early on, but since the charge was to address FAS, it was decided to wait on the report from the ARND subgroup before making the guidelines more specific. The model of FAS and its offshoots, such as ARND, were retained to cast a broad net to get children in the system until there is a behavioral profile to identify those with ARND.
 - C Change "child" to "individual" in the criteria and take out the age range.
- Further Discussions on the Proposed Diagnostic Criteria*
- C The association of FAS with the leading cause of mental retardation is very ingrained clinically. It was suggested to add to #3 "with or without mental

retardation.” (i.e., to say: “obvious structural brain abnormalities, and/or confirmed neurodevelopmental or neurobehavioral disorder in areas of attention, memory, motor function, language, cognitive, and social engagement development, *with or without mental retardation*”).

- C Do not tie a definition to a technology, the use of which is variable, although the educational materials accompanying the guidelines can discuss it.
- C Regarding how to address a child with an obvious FAS face and no history of alcohol exposure, it was noted that a history of alcohol use was not required by the 1989 and 1995 IOM reports, Henry Rosett's report, or by the 4-digit diagnostic codes. It should not be required when the outcomes are extreme. This is important, particularly for the adopted child. It could be a Task Force recommendation to the Scientific Working Group to drop the diagnostic condition requiring history of alcohol exposure if other criteria are met.
- C Racially normed guides, with a standard deviation of 2.5, were strongly recommended by Dr. Astley. Palpebral fissure charts also exist, although they are about as equally insensitive as the growth charts.
- C *These criteria will be helpful, even more so to diagnose other prenatal alcohol-related conditions (e.g., partial FAS or ARND), which affect most of the children seen. Much of these divisions are arbitrary. Is it time to drop the categorizations and discuss spectrums?* NIAAA has elected to use the term, Fetal Alcohol Spectrum disorder. There are too many descriptions of the range between a normal state and full blown FAS, and all depend on how much and when the child was exposed. Perhaps the Task Force should acknowledge that there is an FAS disorder and clarify that these criteria are for that. The FAS terminology still needs to be retained, as the one thing that can clearly be identified and to ensure a clear definition for service provision.

Essential Services for Children with FAS and ARND Subgroup Report

Deborah Cohen and Kathleen Mitchell reported on the work of the *Essential Services for Children with FAS and ARND Subgroup*. A chart of services essential for both the affected child and family across the lifespan was presented. The group adopted a holistic approach. That is, services should be family-centered and must be adapted based on the developmental stage of the child and the needs of the family. Since it is unlikely that states will have resources to develop FAS-specific services, it was felt preferable to make the service system accessible and responsive to a child with FAS.

Dr. Cohen highlighted the services and needs identified by the Subgroup. Examples of the services identified for a FAS/ARND child include diagnostic services, early intervention services, special education services, psychological testing, pharmaceutical interventions, mental health services, skills of daily living, disability services, and housing assistance. Family services include counseling, support services, respite care, how to communicate with service providers, links to community resources, educational materials, and how to be an advocate for your child. The Subgroup reiterated many of the services identified at the first meeting and also discussed the inclusion of additional services such as diversionary programs and alternative sentencing within the criminal

justice system, birth mothers mentoring programs, and services related to prevention and intervening with women at risk of an alcohol-exposed pregnancy.

Many of the essential services needed already exist on some level, but large service gaps are common. Among these are issues related to the justice system and to adult housing services. Dr. Day called for attention to adult services, noting that there is a new psychiatric diagnostic level for FAS.

The Subgroup agreed that there should be a presence in every state to ensure that the systems serving children and families receive materials and education on FAS. The Task Force was in consensus in recommending that this kind of open-system coordination be developed and funded, without over-specificity as to how that would be done in each state. A centralized statewide coordinator, whether in state government, a university or other setting, is desirable. This need not necessarily be a state position/agency, but a site for centralized resources. Optimally, it should be a grassroots-supported, multi-functional entity. Each state should determine how this could be done in their own jurisdiction (e.g, Colorado has a single person, while Washington state fought to avoid a centralized system).

The Subgroup discussed the need to gear mental health services to those with FAS, both out-patient and in-patient. The Subgroup did not discuss the establishment of a DSM code so that psychiatry can be reimbursed without having to identify another diagnosis. But, since so many adults and children with FAS effects end up in mental health services, this is an important concern.

Dr. Snider suggested that the Task Force could advise that states identify the systems and the resources needed to ensure that the essential functions are in place to provide appropriate services (e.g., a piece of legislation), and that the Subgroup follow up on that line of inquiry.

Discussion included:

- C Providers increasingly request evidence-based interventions. The research to date has been too limited to produce sophisticated and proven strategies (e.g., to support that an intervention makes children less likely to drop out of high school), but this should be the aim. Evaluation is needed to produce such evidence, but this has not been funded.
- C Dr. Snider suggested that to increase the evidence base for effective interventions, the Subgroup should consult the CDC Epidemiology Program Office's (EPO) Division of Prevention Research and Analytic Methods (DPRAM) and the Task Force on Community Preventive Services, which investigates evidence-based interventions for inclusion in the Guide to Community Prevention Services. The Community Preventive Services Task Force will review a chapter in production regarding pregnancy outcomes at its October 2002 meeting. Alcohol use during pregnancy is one of the issues they are considering exploring in this chapter.
- C There is now basic science research on restructuring the brain after brain damage,

including that from alcohol. This research has to be piloted and tested then taken into communities for large-scale testing. An evidence base provides further rationale to have such interventions included in program budgets.

- C Caution was advised about over-differentiating between the birth parent and the other types of caregivers in identifying needed services to avoid reinforcing prejudice that could ultimately threaten programs.
- C Additional services suggested for inclusion on the Essential Services list were: nutritional services, physical fitness, folic acid, domestic violence, anger management, instruction for the children with FAS/E on technology (i.e., computers), sex and family life education (contraception, standard prevention, etc.). Adding “having a medical home for the child” was also suggested, but the Subgroup felt that the current health care system puts most services outside the medical home, although a physician may refer clients to these services.
- C A comment was made that while this list identified many good points, long lists often do not get done. Prioritization of the specific needs of FAS or ARND children was suggested, as opposed to those common to all families/children.
- C Dr. Calhoun advised that the Subgroup break down this list to delineate what should be done at all levels (federal, state, local).
- C Emphasis on the need for FAS education was also stressed to make sure it wasn’t lost in the shuffle. A huge investment will be required in the colleges of education to make teachers/administrators aware of FAS and then to provide them with the tools to guide these children from preschool on to independent living. The techniques and strategies used to date have not been evaluated. Evaluation is needed in order to compile and disseminate the wisdom that exists.
- C The Interagency Coordinating Committee on FAS (ICCFAS) includes a representative from the Department of Education. Its representative (Jan Harlow) recently retired but will continue to be involved. Dr. Calhoun reported that she is working to identify an FAS champion from the DOE for the ICCFAS. The ICCFAS will work with their Education Subcommittee to ensure that education issues are addressed at the federal level, but parallel groups are needed at the state and local levels. The ICCFAS Education Subcommittee has supported adding FAS to the reauthorization of Individuals with Disabilities Education Act (IDEA).
- C Dr. Snider advised the Essential Services Subgroup to identify the services that need to be offered and evaluated, at least on a demonstration basis, as well as the selection of seemingly effective services. Determination is needed of the latter’s supportive evidence, the strength of the evidence, and where demonstration projects should be done to illustrate effectiveness. Without evidence on specific interventions, assurance is needed that children with FAS and other prenatal alcohol-related effects receive the basic services that any child needs, because if not seen by a provider at some point, identification of FAS and access to an expert diminishes.
- C A suggestion was made to include a preamble to the Essential Services recommendations that provides a philosophy about a range of needs for children with disabilities (care, home support, etc), and then list the specifics. These should parallel those cited in the Individuals with Disabilities Education Act (IDEA) to make

the issues clear to policy makers.

- C SAMHSA's Center for Excellence in FAS is working to identify the services children are or are not getting. They are working to identify: (1) programs that provide some service relevant to FAS/FAE, (2) the gaps in services, (3) which programs have been evaluated, (4) reported anecdotal successes; and (5) other kinds of needed treatment. This level of detail is needed state by state. The Center hopes to use this information to advise on existing opportunities in health care systems, early education, etc., and to urge that these services be made accessible to those with FAS.
- C Families and service providers need a profile of the entry points that the child will encounter as s/he grows up and moves through the various service systems.

Screening and Diagnosis of ARND Subgroup Report

Drs. Claire Coles and Ken Warren reported on the discussions of this Subgroup. They noted first that the issues related to the screening and diagnosing of FAS have to be resolved before progress can be made on Alcohol-Related Neurodevelopmental Disorders (ARND) or FAS Spectrum Disorder, among other terms for this condition. Pending the guidelines on FAS, the ARND Subgroup met briefly to develop several overriding points about ARND, and their report is attached (Attachment #1).

The working definition of ARND used by the Subgroup is that "Alcohol-Related Neurodevelopmental Disorder (ARND) is neurodevelopmental teratology that is caused by pre-natal alcohol exposure. It may be of varying degrees of severity. In a given individual, it may be difficult to differentiate neurodevelopment problems that arise from the alcohol exposure as distinct from other causes. Certain traits may vary with developmental age or stage. It is expected, though not definitive, that the types of neurodevelopmental deficits observed in FAS will be present in ARND. Therefore FAS is a starting point for fully defining the nature of the deficits in ARND."

The group agreed that the behavioral problems of FAS are seen in children not meeting FAS criteria, but ARND has received much less attention. The Subgroup called for a meeting on ARND of professionals from the different related fields (e.g., education, child psychiatry, school psychology) to address the issues of ARND's barriers and challenges. Current nosology is inadequate to reflect the current understanding of this disorder. Behavior-based guidelines are needed, as is research into the distinguishing features of ARND from similar disorders such as ADHD. Research is urgently needed to develop the evidence base to delineate the full range of ARND dysfunction, especially across exposure levels. The Subgroup called for larger sample sizes to better delineate ARND's subtle effects, research into the influence/interrelationship of parental and social environments and organic damage, attention to the global health impact of prenatal exposure to alcohol, and investigation into ethnic variations in vulnerability to prenatal alcohol exposure. Also needed are longitudinal studies of changes in development, the manifestation of the disorder at different developmental stages, and changes in individual children with the disorder across the life span.

Dr. Coles commented that the "varying degrees of severity" in the working definition is an understatement, but ARND is indistinguishable from FAS except from the facial syndrome. Without that, or evidence of mental retardation, a differential diagnosis is difficult. Given that and that ARND is more complicated than FAS, some may ask why even attend to it now? The answer lies in the fact that every assessment to date indicates that ARND is more common than FAS – perhaps by an order of magnitude (Streissguth, et al).

Discussion included:

- C The term Fetal Alcohol Spectrum Disorder (FASD) does not highlight ARND's neurodevelopmental aspect, about which the community needs to be educated. The spectrum concept is nothing unique to those dealing with genetic disorders (e.g., there's no discussion of a Down Spectrum). As a behavioral teratogen, alcohol affects the brain; some think that most of the facial effects are secondary to brain effects.
- C Despite the fact that this really is a spectrum disorder, the hard-won recognition of FAS as a valid concern requires its retention as a term, and its recognition can be built upon to promote awareness of ARND.
- C There is yet no identified behavioral phenotype for alcohol exposure, although Dr. Coles, NIAAA and other agencies are exploring that. There is no way, and may never be a way, to identify alcohol as the cause of anything.
- C Until the definition of FAS is extended to include the ARND definitions, differentiation between FAS, FAE, etc., will have to remain.

Screening and Intervening in Prenatal Alcohol Use Subgroup Report

Dr. Sokol stated that what should be done to prevent alcohol-related perinatal damage depends on the variability/variation of FAS. There are different prevalences for FAS and other fetal alcohol effects among populations, differences in drinking amounts and patterns among individuals, variability in susceptibility, and a range of effects. To factor in all of these considerations, Dr. Sokol suggested using an at-risk strategy.

High Risk. High risk situations include high-prevalence populations and the presence of factors suggesting increased susceptibility, such as maternal age >30 or massed ("binge") drinking (e.g., 4-5 drinks an evening on an average of once or twice a week). The 1996 IOM report by Stratton *et al* defined a spectrum of FAS interventions, including screening to identify those whose drinking is sufficient to damage a child. But the great challenge to screening is denial, a problem that probably is worsened since women who drink during pregnancy are stigmatized.

There is also physician denial. A study of why Michigan physicians did not screen women included reported feelings of discomfort to address the topic, an inability to help (true abusers will continue regardless), reluctance to offend, and denial by both patient and physician (e.g., "After 20 years, I know my patient.").

Two screening tests include the T-ACE (physical Tolerance of alcohol, Annoyance at

criticism of a person's drinking, need to Cut down, need for an alcoholic Eye-opener to start the day) and the TWEAK. Both are sensitive and specific to screen-positive patients and those for whom there is clinical suspicion that calls for special attention to their drinking. Often, a brief intervention will be adequate, although extended interventions (even a couple of times) are also effective.

Low Risk. At the other end is the low risk setting (low prevalence), in which the best course is probably to advise all reproductive age women not to drink if they are pregnant or could become pregnant.

Dr. Sokol and Natalie Roche co-chaired the Subgroup and an outline of their report is attached (Attachment #2). Most of the discussion focused on high- and low-risk settings, with examples of each, appropriate prenatal screening tools (as endorsed by ACOG), methods for determining when more in-depth screening procedures should be used, and intervention options with a focus on brief and extended counseling interventions that can be administered by physicians or staff (e.g., grief talk therapy, CBT and motivational interviewing). Advice coming from the care provider is very powerful. Also discussed was the need to have a systematic review of the available interventions for women.

The Subgroup's first draft of recommended interventions for physicians is shown on the attachment's chart, and presents examples of high risk settings. At the first prenatal visit and at subsequent visits, the physician should ask all low risk women about drinking and advise abstinence for a healthier baby. Any suspicion of drinking would move the woman to a high-risk protocol, doing the T-ACE or TWEAK and interventions as needed.

Discussion included:

- C *"Just say no" will not work for someone drinking heavily, and many doctors still say that a few beers will not hurt you. For many people, drinking is a way of life, similar to drinking sodas and smoking cigarettes. It is not only irresponsible but dangerous to tell a woman that any amount of alcohol use in pregnancy is OK.* The issue to be addressed is what to do overall in high risk situations. To say do not drink at all is a fine message, but the high risk group still must be addressed. What the physician tells a woman in the office is not necessarily the public health message. The situations between talking to someone before and after the fact are different.
- C *Did you consider in the high risk population what the intervention would be for those women who are alcohol-affected themselves? An FAS-affected mother will not change behavior from talk, even repeated talk.* There are no transgenerational data available yet; the first cohorts only now are maturing. But one woman at the meeting reported that her foster daughter is a fifth generation FAS individual, and that population has to be researched. The current prevention message has no effect on this population at all.
- C Dr. Day suggested adding to the category of high risk women those who abuse other substances such as other drugs and tobacco, and expanding further to explore

psychological problems. The age cut also needs to be carefully considered and incorporated into a screen.

- C Since heavy episodic drinking puts embryos at most risk, an instrument to screen for that may be more efficient and provide more potentially useful research data. The AAFP published a screening tool for the primary care setting to explore heavy drinking, which was validated by people presenting at an emergency department. Its method of asking "How long since you had "x" number of drinks in one day" (for men, x was 5) seemed not to offend. Other questions explored whether the person "ever thought they should cut down on drinking," and "when was last time they had >5 drinks in one day." Those questions or a variation such as "What was the most you drank on one occasion in the four weeks before you learned you were pregnant?" may avoid a defensive answer.

Dr. Damus commented that, similar to ACOG's recommendation asking for assessment of domestic violence once per year, this recommendation needs to be clear that it is asked of all women. Most commonly, prenatal care will be focused on other conditions, and pregnancy is a situation in which women are more likely to be concerned about the health of their baby. This needs to be integrated into other initiatives such as not smoking and folic acid. A way must be found to ask these questions respectfully and not judgementally. Dr. Vinson and Dr. Damus volunteered to work with this subgroup in their future deliberations.

With no further comment, the meeting adjourned at 5:00 p.m. and reconvened at 8:08 a.m. the following morning.

SEPTEMBER 21, 2002

Report on SAMHSA/CSAP Stakeholders Meetings

A report on the meeting of stakeholders of the Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Substance Abuse Prevention (CSAP) was provided by Mr. Dan Dubovsky and Ms. Jocie DeVries.

CSAP Overview. Mr. Dubovsky outlined the CSAP mission, as mandated by legislation:

- C Study adaptations of innovative clinical interventions and service delivery improvement strategies;
- C Identify exemplary community systems of care;
- C Provide technical assistance to communities;
- C Train professionals, families, community leaders and others on the implications of FAS/ARND;
- C Develop innovative techniques for preventing alcohol use by women in child bearing years;
- C Perform other functions, to the extent authorized by the Secretary, after consideration of recommendations made by this Task Force.

The CSAP's goals are to reduce the rate of births of infants affected by prenatal alcohol exposure and to improve the quality of life for individuals affected by FAS/E and their families. The vision to accomplish this includes a nation without fetal alcohol syndrome; an integrated collaborative approach to FAS; communities expert at implementing effective, scientifically tested prevention and treatment programs; exemplary community systems of care for those affected by prenatal alcohol exposure; and communities that share experiences and lessons learned. The CSAP Steering Committee co-Chairs are Dr. Riley and Dr. Calhoun.

Activities to date were outlined:

- C Formation of a steering committee to provide advice and guidance to the Center. Workgroups were established to address the federal mandates.
- C Six town hall meetings were conducted across the country from March to August 2002.
- C Trainings on FAS were presented at regional and national conferences.
- C Technical assistance was provided to parents of individuals with FAS/E, service providers, and federal FAS prevention grantees, and a meeting was held for the CSAP grantees.
- C An environmental scan was done to develop an in-depth inventory of scientific and popular literature and existing prevention and treatment programs.
- C A poster for conference presentations and an information and resource database was developed. A web site is currently under construction (<http://fascenter.samhsa.gov>).
- C Networking between the Canadian Center of Substance Abuse and Health Canada began to develop international initiatives.

The *environmental scan* involved identification and review of existing training and educational materials, the identification of existing prevention and treatment programs, an assessment of FAS specificity for each program, and the identification of best practices and gaps in research and practice.

Gaps identified included:

Screening of women at risk

- C Existing screening methods are not routinely conducted in prenatal care.
- C Many instruments only identify women with the most severe alcohol problems.
- C Lack of a stepped approach to screening.
- C Instruments typically do not screen for co-occurring disorders.

For those individuals who may be affected, screening is hampered by:

- C The need for continued research on biomarkers
- C Lack of a standardized stepped approach to screening and diagnosis
- C Lack of screening in systems of care
- C Lack of screening for co-occurring disorders
- C Lack of consensus on a diagnostic procedure
- C Lack of standardized training curricula

- C Paucity of evaluated prevention programs
 - Few evaluated public health education programs focused on FAS
 - Lack of use of evidence-based procedures for selective FAS prevention
 - Lack of services for women at risk

Treatment is hampered by the lack of services for affected individuals and the lack of controlled studies of treatment strategies.

The next steps will be to evaluate programs, educational/training materials, and websites. Expert panels will be involved to identify best practices, create a national centralized, accessible resource database, and develop a database of researchers, research interests, and funding sources in collaboration with Canada. The development and implementation of pilot interventions will be facilitated, as well as further identification of gaps in prevention and treatment. Systems and programs that should have an identified focus on FAS but currently do not need to be identified.

Discussion included:

- C *Does the evaluation include community/volunteer programs?* Yes, everything is being evaluated. Mr. Dubovsky solicited names of known programs for the Center to contact.
- C *Is the evaluation funded?* That is in development.
- C *What professional groups were trained?* This generally was done at conferences, one of them being on drug treatment. A list of the professional groups that were trained can be provided.
- C To the CSAP vision of "a Nation without FAS," add "... and without future births affected by FAS."

The report of the ***Town Hall Meetings*** was presented by Ms. DeVries from FAS Family Resource Institute. At the first CSAP steering committee meeting in February 2002, it was agreed to hold six town hall meetings to take testimony from families and professionals about FAS, an area in which the FAS*FRI is experienced. The testimony will be given to Congress this month. The meeting sites included Washington, Colorado, Texas, Florida, Illinois, and Michigan. Each site had strong organizations with well-connected contacts to organize these meetings in a short period of time. The meetings were also advertised through the FAS*FRI's newsletter, "FAS Times."

Ms. DeVries outlined the meeting process, from distribution of the brochures to state health agencies, and programs on chemical dependencies, criminal justice, education, etc., to the gathering of verbal testimony from 224 individuals to VIP panels in each state. A good number of state leaders heard the testimony and were inspired to address the issue of FAS and the previously unknown toll it takes on their agencies. Written testimony was also accepted, and a book of those sent to the FAS*FRI was shared with the Task Force. CSAP bound the meeting testimony in a yellow book as a companion book to the Town Hall Meeting's recommendations.

Many parents were skeptical that CSAP would help. The FAS*FRI hopes that the reports from the 2002 town hall meetings will help those parents trying to access services to prove that FAS exists and to support the complexity of the disability. The books present the common experience of families raising children with FAS. An evaluation component will follow up to check if the books reflect what was said at the meetings. An educational CD-rom was also developed by the CSAP to give to Senator Daschele and FAS*FRI plans to copy this to help families work with their physicians and others they encounter (e.g., educating them on the core behavioral disabilities).

Anger was expressed at the town hall meetings that, with all the funding spent in the last 30 years, little has supported the programs that encourage and mentor the families. For example, a curriculum was developed years ago for teachers about dealing with children with FAS, but never funded for dissemination. All the contributions done to date have come from advocates like Barbara Wybrecht.

One big gap in the town hall meetings was that very few birth mothers attended. A "Birth Mothers' Summit" is planned to obtain their testimony, and may be held in March 2003, depending on funding cycles. In 2003, town hall meetings will be held in Mississippi, California, New York (Buffalo), Washington D.C., Arizona and South Dakota. North and South Dakota will do educational programs and pre- and post town hall meetings evaluations.

Mr. Dubovsky reported that all the panel members left the town hall meetings impressed that something must to be done about FAS. The meetings identified many needs, including:

- C Respite care.
- C Understanding of FAS by various systems of care, including education, mental health, substance abuse treatment, corrections, vocational programs, health care, and income programs such as medical assistance and Social Security.
- C Accessible facilities for diagnosis.
- C Appropriate services for affected individuals and their families in every system of care (including appropriate residential services).
- C An array of appropriate, accessible, and available housing options.
- C True individualized programming.
- C Adequate training of all providers working with individuals with FAS/E and their families.
- C Psychiatric expertise on psychopharmacology for individuals with FAS/E.
- C Effective prevention strategies.
- C Best practice models of substance abuse treatment for pregnant women and women with children.
 - Discussion of FAS/E in treatment programs.
 - Recognition of possible prenatal alcohol exposure in those in treatment.
- C Treatment centers for women with children who have disabilities.
- C Transition services for children as they age out of child serving systems.
- C Adoption subsidies.

- C Disclosure laws that enforce the discovery and sharing of prenatal substance use history to families.
- C Estate/trust planning.
- C Funding for programs that work with families, especially grass roots programs.
- C Acceptance of one's disabilities due to prenatal alcohol exposure.
- C Lifetime advocates.
- C Appropriate, supportive social outlets.
- C A clear message to physicians concerning alcohol use during pregnancy.

Recommendations for the Future for all to consider include:

- C A coordinated, collaborative effort to prevent and treat FAS.
- C Achieving consensus in terminology, assurance that persons with FAS/E qualify under the federal classification of developmental disability and that states follow the federal definition, and recognition of FAS/E as a co-occurring disorder.
- C Screening and diagnosis issues include: establishing a standardized diagnostic procedure, developing standardized, validated screening tools for FAS and FAE, identifying methods for early screening and diagnosis, providing routine screening in multiple systems of care, and providing access to diagnosis.

Recommendations for the Future - Prevention:

- C Increase the awareness of the dangers of drinking during pregnancy and FAS.
- C Deliver the clear message that there is no known safe amount of alcohol use during pregnancy as well as a clear message about not drinking during breast feeding.
- C Promote universal screening for alcohol use during pregnancy in a comfortable way that encourages disclosure.
- C Provide training to health care providers in asking women about alcohol use.
- C Improve access to treatment for women with alcohol problems who are pregnant or have children.
- C Provide case management or other treatment services in the settings where women at risk are seen.
- C Ensure that written materials are available in health care providers' offices and that signs are available for posting in physicians' offices about the consequences of alcohol use during pregnancy and about FAS.
- C Increase awareness and knowledge of FAS/E across all systems of care.
- C Screen women at risk for their own prenatal alcohol exposure.
- C Develop/promote programs/approaches for these women that are tested and validated.
- C Ensure greater visibility of FAS on the agendas of organizations (e.g., Healthy Mothers, Healthy Babies now do not address FAS).

Recommendations for the Future - Treatment:

- C Develop national standards of care for individuals of all ages with FAS/E and their families.

- C Encourage research to validate treatment strategies for those with FAS/E.
- C Make affordable respite care available in all communities.
- C Ensure knowledgeable treatment personnel in all systems of care.
- C Require initial and continuing education training in FAS/E in all systems of care.
- C Require knowledge of FAS/E for licensing and certification.
- C Increase the skills of educational personnel to work with children and adolescents with FAS/E and their families.
- C Provide supports to families.
- C Include FAS/E in the DSM.
- C Encourage research and expertise in psychopharmacology for individuals with FAS/E.
- C Develop specialized corrections approaches for individuals with FAS/E (e.g., diversion programs, including alternate charges (e.g., minor sexual offenders with FAS who do not understand what they have done wrong still have to be so registered for the rest of their lives).

Policy Recommendations:

- C Encourage/require states to recognize persons with FAS/E as being disabled, regardless of I.Q.
- C Require mandatory training on FAS/E for all staff working with individuals with special needs.
- C Require posting of warning signs on the dangers of alcohol use during pregnancy at point-of-sale establishments.
- C Recognize FAS/E as specific diagnoses for eligibility under IDEA, SSI, and other federal benefit programs.
- C Encourage states to target women of childbearing years who have alcohol and drug problems for nonabortifacient contraceptive services.
- C Increase allowable earnings and assets under SSI for those diagnosed with FAS/E without losing medical coverage (e.g., >\$2000 in assets loses coverage).
- C Encourage states to adopt/enforce disclosure laws in foster care and adoption system.
- C Ensure that psychiatric medications that might be used in children/adolescents with FAS/E are tested for use in that population.

Discussion included:

- C One of the best outcomes of the town hall meetings was the collaboration that resulted. Federal and state panel members were in policy making positions; the families had their names and could make them accountable after the meetings. All the Task Force members' attendance at these meetings was encouraged. Dr. Riley and Dr. Schad called them "eye opening experiences."
- C A separate meeting in an environment where birth mothers feel comfortable to tell their own stories is necessary. There was so much anger at these meetings that it was too risky for mothers to speak. Their stigmatization will continue to carry over to the children.
- C Again, the town hall meeting attendees commented on the importance of developing

a FAS phenotype.

- C Dr. Snider commented that these town hall meetings could also contribute to qualitative research to tap into how some of these problems can be addressed
- C *Agency funding can help to convey the needs/messages to states about what is needed (e.g., get information to women in treatment about FAS, effective contraception and where to get those services, and appropriate FAS treatment). What would you identify now that is needed?* The answers included:
 - < Training for all who might encounter persons with FAS/E.
 - < Educate on FAS core disabilities, to know what they are, and extensive intervention training in each system.
 - < Support existing experienced family networks and birth mothers, and training them as trainers in the chemical dependency field.
 - < Develop exemplary community systems of care and develop/promote effective prevention programs with treatment as an essential part of prevention for those with FAS/E.
 - < Train health care professionals must begin with inclusion of FAS questions on the licensing exams.
- C *What concrete steps will be taken to ensure that work with state officials happens?* SAMHSA's block grants specify what the state must do; at one time, a rider required 10% of funding for drug treatment go to pregnant women. Many agencies have interactions with states, but this is a systems problem requiring address by everyone: HRSA, SAMHSA, CDC, etc.
- C To provide schools the needed services, a cadre of trained, educated, informed people to educate on FAS/E is needed. South Dakota, until losing funding a year ago, held 6-7, 2-day workshops. Dr. Schad was convinced that this is on the right path, but improvements are needed, as is a pre-/post- evaluation. He agreed to provide information on South Dakota's work and proposed it be used as a demonstration project/pilot program to educate teachers in the field, and later, to graduating new teachers. He offered to coordinate that. The pilot would then be transferred to state programs. Dr. Floyd reported that CDC is developing grants for teacher training which, after evaluation, will be disseminated.
- C The traditional top-down method of researching, until interventions are implemented in the field, can overlook some approaches. Field experiences need to be nurtured. The Task Force should identify promising approaches in the diagnosis/treatment of individuals and their families and work with those groups by providing funding/expertise and attaching evaluation components to those likely to be disseminated to the field. A mentoring program to help local communities gather the data on what works also could reduce redundant research.
- C Ms. McKinney strongly supported grants that meet the needs of the people affected, rather than being so broad as to not be valuable, and the awarding of these grant funds to those who are making a difference in peoples' lives.
- C Dr. Riley suggested a sustained e-mail conversation about how the Task Force could implement a procedure to do environmental or pilot projects with less than the usual scientific rigor, while still ensuring that the money is well spent.

Key Concerns of Biological Mothers of Children With FAS

Ms. Kathleen Mitchell, and three mothers of children with FAS, Ms. Angelina Locklear-Taylor, Ms. Diane Malbin, and Ms. Marceil Ten Eych, presented their concerns to the Task Force discussing the unique issues of being a biological mother of a child with FAS.

Women and Alcohol: An Overview

Ms. Mitchell commented that, while the leadership on work to address FAS includes brilliant minds, the issues are also sometimes over-complicated. She did not expect much success in defeating FAS until it is re-emphasized that alcoholism is a disease. As a recovering heroin addict, she did not use heroin during her five pregnancies, but drank wine, thinking that was not harmful. One of her sons died shortly after birth and another little girl, of good size, died of SIDS at 3 months. A connection to her alcohol abuse was never made, and this must be changed.

Background. Many people think that the birth mothers of children with FAS are bad and unethical. Most parents who call the National Organization for FAS (NOFAS) are adoptive parents who figured out on their own that their children have FAS. The telling signs indicating that women may have an addictive disease are often not noticed, and the problems of their children are often attributed to other factors such as the chaos of moving around a lot, not eating properly, etc. The women themselves also are frequently not able to realize the trouble their children have.

Of the estimated 15.1 million alcohol-abusing people in the U.S., approximately 4.6 million are women. Alcoholism is defined as a primary, chronic disease with genetic, psychosocial, and environmental factors influencing its development and manifestations. An estimated 60% of females over age 18 drink; 85% are more likely to drink alone, 30% in Alcoholics Anonymous are female, and the death rate is 50-100% higher for alcoholic women than for alcoholic men. Drinking behaviors differ with age, life role, and marital status. Younger women (age 18-34) have higher rates of drinking-related problems, but middle aged women have a greater incidence of alcohol dependence (age 35-49). Alcohol-related problems are the third leading cause of death for women aged 35-55.

Physicians continue to enable women, who are less likely to be screened for substance abuse problems. Marketing by the alcohol industry also enables women's drinking, and so does the legal system. Women are far less likely to suffer legal consequences and are less likely to be questioned about consuming alcohol. Identifying women can be difficult, since there is greater denial and minimization of the extent of the problem. Although women represent 25% of the clients in traditional treatment centers in the U.S., it is estimated that only 14% of women who need treatment actually receive it.

In a national study, women identified three major barriers to addiction treatment which include the inability to admit the problem, lack of emotional support for treatment from

family members, and the inability to provide adequate care for their children. Other barriers include low income/poverty, violence/domestic abuse, child care, disability or children with special needs, transportation, cultural/language differences; program or bed availability; and the fear of losing their children or of criminal prosecution. Most women presenting for treatment have low self-esteem, little self-confidence, and feel powerless. They are often in codependent (abusive) relationships and a high percentage of those in treatment report sexual or physical abuse.

The uninformed attitude even among health care professionals is "no solution, no problem," based on the belief that there is no cure for "those" women. Many students believe that these mothers "are bad, crazy, and have too many problems."

Streissguth's research among women who bore children with FAS noted a very high rate of obvious mental health disturbances. But the reality also is that anyone taking cocaine and alcohol, for example, will exhibit inappropriate behavior that psychiatrists can tag with multiple diagnoses.

The barriers to women getting treatment include:

- C False assumptions in the medical community that: women know about the dangers of prenatal alcohol use (especially non-minority women with a higher SES); all women know that beer and wine are also alcohol; and the general public (young women) know what FAS is.
- C Physicians say that women with alcohol problems are the hardest women to reach. Sophisticated counseling skills are needed, treatment can be very expensive and time consuming, there are not enough treatment beds available and treatment does not work for those women.

In Ms. Mitchell's opinion, the solution is very simple: "just SAY it." But FAS/ARND is a "scarlet letter" bearing a lifelong stigma for the individual, the mother and the family. The diagnosis implies purposeful harm and results in shame and embarrassment. It also sometimes requires explanation in inappropriate settings. To increase the possibility of intervening with these women, the paradigm must be changed to reflect that there is a solution; that brief interventions do work; and that high risk women are treatable.

Ms. Mitchell wished for a "no brainer" checklist for pediatricians that would help providers identify "red flags", such as, frequent family relocations; an unusually high frequency of doctor visits; a child's failure to thrive; many prescriptions for antibiotics; missed appointments, sleeping/eating issues; reports of paternal alcohol use; etc.

Supporting birth families is important. Recovery from addictive disease is a process and avoiding relapse requires many factors, including: 1) case management services to help them move through the system and through recovery; 2) respite care; 3) community/family support; 4) long-term monitored outpatient care (proven effective by research); and 5) a public awareness campaign to reduce the stigma for birth families.

Discussion included Dr. Snider's summary of two main messages from this presentation: 1) the "silo mentality" of scientific research can sometimes make us "stupid" and 2) new knowledge is shifting the public health paradigm from that to a systems approach. A better understanding that any particular problem or disorder often has multiple etiologies is needed. Choices are made in life, but individuals are also affected by their social environment, genetic makeup, etc., in a complex set of circumstances. This understanding needs to penetrate much better into the scientific and medical community.

Personal Stories from Birth Mothers

Ms. Locklear-Taylor was certain that her physician had to know that she drank during her pregnancy since anyone could smell beer on her breath. Her son is now on death row, having killed her husband. She did not know he had FAS until a friend, who is a school social worker, suggested it. Although there was no premeditation on her son's part and an expert explained the effects of FAS, the judge in Robinson County was unimpressed. She has had people blame her directly for her son's crime. Her son's teachers reported to the attorneys that he never gave them any trouble, but every one "just knew something was not right." Because he was so far behind his classmates academically, he often left school just to get away from the situation. Her own stigma relates not only to having a child with FAS but also to being an American Indian.

Ms. Ten Eych's parents were a physician and a pharmacist. She has a daughter and stepdaughter with FAS and FAE. She maintained that mothers and FAS patients are invisible and that no one believes them when they seek services. She herself was a Girl Scout executive, and her husband was a Naval investigative service/alcohol special agent. Their drugs of choice, alcohol and prescription drugs, were never illegal and they were never screened ("who would ask a Girl Scout executive or a 'narc' if they drank?" she asked). Her mother, who was an exemplary community member as well as an alcoholic, drank for 20 years. She developed cirrhosis of the liver and was in a coma for sometime. The medical records never cited alcohol, but mentioned that her prognosis was poor because of her "other (unnamed) problem."

Ms. Ten Eych stated that women still lose their children. She lost hers when she was in treatment. Women also risk being jailed for abusing their child if they drink in pregnancy. Treatment would be better. She related her anger at a broadcast in which Dr. Laura berated a mother for letting her daughter out alone, when the daughter was impregnated at a church picnic. There is little understanding of the challenge to parents of children with FAS/E to balance protecting their children, letting them go, letting them be advocates, etc.

Ms. Malbin's parents had the same occupations as Ms. Ten Eych's. She stated that the right questions are still not being asked. She went into recovery after her children were born; the question is, what should have been asked before they were born? She asked why the collusion continues between people in key positions who do not discuss the problem. Addiction and alcoholism have parallel characterizations of the "no solution,

no problem” paradigm. The prevailing presumptions about children with FAS is that they are hopeless.

Ms. Malbin focused on brain function as one key piece of the FAS puzzle. She suggested it is time to relate the implications of neurological damage to the understanding of disability. Sophisticated techniques and interventions have been developed for individuals, but neurocognitive theory research remains largely unintegrated into programs. The goodness of fit remains unanalyzed between the basic assumptions of the programs and the neurocognitive reality that research has supported. When she was in prenatal counseling, there were already over 2,000 peer-reviewed papers published on prenatal care, but alcohol was never mentioned, nor is that knowledge yet applied to help her daughter in school. She expects that neurocognitive theory will provide one alternative theoretical foundation for understanding constellations of behavior that consider other kinds of mental health problems. It redefines the problem and the point of intervention. Children with FAS cannot store information and make the connections. In 1954, the brain function relationship to processes was understood; why has it not been applied? What is needed is a context in which the understanding of behavior is linked to the research on that and brain function. That can re-craft the questions and help to design responsive programs and policies.

Discussion

Dr. Susan Astley commented on how closely these stories parallel those of 80 mothers of children with FAS who participated in her research study. She commented that the mental health burden on the children is even higher among the birth mothers. The study compared women who were successful in abstaining from alcohol to those who did not, and found that the abstainers did not have a lower mental health burden. The two groups had, on average, 4-5 other mental health disorders aside from alcohol abuse. The difference was that those who stayed sober had received treatment for mental health.

Health Canada's FAS Activities

Dr. Julie Conry, the Co-Chair of Canada's national FAS advisory committee, presented for Dr. Jocelynn Cook, who is on Health Canada's FAS/FAE Team. The Canadian FAS/FAE Team is charged with conducting:

- C Health promotion education and awareness: Health Canada has administered a national health professionals survey to determine knowledge and attitudes about FAS/FAE and are working towards standardized guidelines for diagnosis, screening and surveillance (there are currently nine clinics in Canada).
- C Public education and awareness: An FAS toolkit and fact sheets were developed, articles were placed in maternity magazines, public inquiries were answered, and posters, pamphlets and a Website were produced.
- C Research: A researcher database is being developed to facilitate FAS research and disseminate research results.
- C National Framework for Action: Through consultations with stakeholders, they

developed a common vision and outcome measures to improve the quality of life for Canadians affected by FAS. The framework is being finalized, and a plan for communication and dissemination is in development.

- C Strategic Project Fund: supports a grant process to 7 community-based projects and evaluates them for best practices.
- C National Advisory Committee was established by the Ministry of Health in June 2000. Its seventeen members from across Canada represent diverse expertise and experience, who recommend to the Minister of Health about FAS-related issues. After their first year, they proactively offered recommendations, and responded to a Ministry's request to recommend labeling of alcohol beverages. Subcommittees were also developed which will make additional recommendations on: a) the quality of life for FAS-affected individuals and their families; b) public education (all professions), and c) screening, diagnosis, and surveillance.

To standardize screening, diagnosis and surveillance, Health Canada formed a committee to recommend national guidelines for FAS/FAE screening and diagnosis. The discussion has centered around terminology (Fetal Alcohol Spectrum Disorder – FASD), screening tools, diagnostic procedures, surveillance, and the feasibility of standardized National guidelines. The committee will:

- C Develop recommendations on steps to obtain national consensus on diagnostic guidelines.
- C Address training, reporting, and surveillance. They are developing a birth defects registry that records such diagnoses by codes as well as terminology understandable to the public. This dynamic registry can be updated, and Canada's healthcare for all will enable database linking and perhaps tracking.
- C Obtain consensus on research needs and capacity building in these areas. Dr. Cook was awarded a grant to assemble researchers to discuss this.

The discussions on terminology centered on the use of Fetal Alcohol Spectrum Disorder. It offers the advantage of recognition that this exists along an entire spectrum and parallels Autism Spectrum Disorder. However, it has no specific criteria. There also is concern that it may become a catch-all for children with problems and may over-represent the condition, as occurred with autism's exponential rise in diagnosis since it entered the public domain.

The advisory committee recommendations were as follows:

Terminology:

- C FASD is an umbrella term that suggests that alcohol is a factor in this child's development. It is not a diagnostic term.
- C Clinicians may use the term FASD for the purposes of screening and referral, which should lead to a more formal interdisciplinary diagnostic process (using established definitions of FAS and related conditions - reference: IOM, p.79 and Minutes of the Committee, June 5).

- C FASD cannot be used when it is known that the mother did not drink alcohol during pregnancy.
- C Parameters for the use of the term outside of the medical/clinical community need to be developed. In the medical community, only people with the broader knowledge of FAS diagnostic terminology (IOM) should use this term.

Diagnosis. The National Advisory Committee and Health Canada were advised to establish an expert panel to develop national standards for diagnosis of FAS and FAE. This meeting is planned for October 6 in Winnipeg.

Screening:

- C Based on available information, the committee believes there is no reliable screening tool currently in use with demonstrated validity (and specificity) to predict FAS. Discussion focused on tools incorporating learning and behavioral deficits for use by non-medical professionals.
- C Screening cannot be equated with diagnosis. If the purpose of screening is to get these children to the diagnostic clinic, then there must be clinics and services available initially and for follow-up.
- C Research is needed into developing effective, sensible, and reliable screening protocols. There is much interest in this by social workers, community health nurses, and justice workers.

The next steps will include more discussion about screening and surveillance issues, the issue of FAS diagnostic training, research priorities and capacity building (pursuant to the recommendations from the Canadian FAS Research Priority Setting meeting), and gaining consensus among Canadian diagnostic clinics as to which recommended method of diagnosis should be used.

Discussion included:

- C *Is Canada doing anything unique/different that could help U.S. activity?* They are beginning to develop diagnostic facilities and better norms for the nation's groups. Joint work can be done on tracking FAS with the changes in physical development as the child matures and to help develop diagnostic expertise. The health care system also should have facilities to treat pregnant women.
- C *What registries and system will be used, who would be included and using what definition?* The four digit numbers facilitate this as the numeric character allows examination of the spectrum. Registration of birth defects probably will be done on a community clinic-based basis.

Public Comment

Ms. Jo McKinney is the mother of 13 year-old child with FAS and a member of the Georgia Task Force on FAS. She defined Georgia's challenges as a lack of early intervention, lack of occupational or physical therapy services, and lack of awareness by teachers including those in special education. In 1999, FAS was brought to Gov. Barnes' attention and he created FAS Awareness Day. She believes that only federally

mandated guidelines will ensure that services to her daughter and other children with FAS will continue in Georgia. She hoped that this Task Force would recommend: 1) a national mandate that each state have an FAS coordinator to coordinate services throughout the state and help families negotiate the system; 2) guarantee funding for a diagnostic center in each state to ensure the important early intervention; and 3) assurance that these two recommendations are effectively implemented through an annual meeting of state coordinators to facilitate cross-communication.

CSPI Proposal. Mr. George Hacker, from the Center for Science in the Public Interest (CSPI), was very touched by the stories told and impressed by the broad range of participation in this meeting. One way to raise awareness about FAS and the dangers of drinking during pregnancy is through alcoholic beverage warning labels. Last year, the CSPI called for revised design specifications on these labels, a petition that is still pending at the Bureau. They asked that the label be horizontal, boxed in upper/lower case, and have a picture to attract attention. The current law, regulated by the U.S. Bureau of Tobacco, Alcohol and Firearms (BATF, part of the U.S. Treasury), allows the warning label required on alcohol containers to be put anywhere. In many cases, it is clearly meant to be lost (e.g., printed on the bottle cap in an unreadable font). Mr. Hacker hoped for support of this petition to the Treasury, and that this Task Force would recommend that the DHHS Secretary communicate to the Secretary of the Treasury about this labeling issue. He also asked participants to forward copies of any point of service signs required in many places about drinking in pregnancy, since the CSPI often get requests for help regarding that as well.

Dr. Riley asked that any Task Force member wishing to advance that recommendation to the Secretary send it to him. Mr. Hacker offered to draft a resolution which will be circulated to the Task Force members. Dr. Day encouraged that this be done promptly, since the BATF may rule on this soon. The CSPI evidence has been attacked by the alcohol industry.

Teratology Society Proposal. Dr. Jones distributed a statement of the Teratology Society's Public Affairs Committee. It will be published in the journal *Teratology* soon and they hope also to publish it in *JAMA* and other journals for greater circulation. He asked if the Task Force would like to jointly author this with the Teratology Society. *JAMA* will publish previously published material that relates to public policy issues, as done for the U.S. Preventive Services Task Force's statements. All that is required is disclosure that it has been submitted to multiple venues.

Discussion included issues raised that will be marked by the Task Force members on their copies of the document:

- C Clarity that this is not a "minority issue."
- C A greater focus on preconceptional intervention opportunities (e.g., upon a negative pregnancy test and with young women).
- C Use the word "guidelines" rather than "standards."
- C Clarify the comment on page 1 that birth mothers are often "unwilling..." This implies

that they are just hard to work with, rather than suffering/dealing with a disease.

Dr. Riley asked the members to read these guidelines carefully. If a consensus is reached to endorse or co-author them, the edits will be circulated and the document will be sent it out electronically. Since Task Force products also need to go through the approval process, he asked that this be done expeditiously.

Federal Agency Updates

ICCFAS/NIAAA

Dr. Calhoun reported on the Interagency Coordinating Committee on FAS (ICCFAS). As issues arise, its 10 member agencies/organizations, which are all systems of care, invite other pertinent organizations into the discussions. The Agency for Health Care Research and Quality (AHRQ) is just waiting for some implementable intervention to conduct. Some of the agencies run parallel activities (e.g., SAMHSA runs the CSAP and others such as the 5-state consortium; CDC manages the Task Force and does surveillance/research projects, etc.). Each organization has priorities and broad missions. Since 9/11, the Department of Justice's (DOJ) activities are being reduced to shift funding to the war, so it is harder to even get FAS on the discussion agenda there.

However, activity since last December includes:

- C The ICCFAS's report on FAS was issued. It included a strategic plan, indicated progress made, and featured results of research and demonstration projects by the member organizations. Their May meeting included reports of progress on basic research that offers potential for medicines and interventions.(e.g., the National Center of Child Health and Human Development research on peptides' ability to prevent alcohol-related fetal death/injury).
- C An ICCFAS initiative with Washington, D.C. to reduce infant mortality tested a CAD tool to screen high risk women and reported that ~12% of District women at high risk drink during pregnancy. Follow-up is planned.
- C Ms. Harlow's Education committee, which is funded by and reports to the ICC and NIAAA, has issued a number of recommendations on education.
- C For those health care providers not interested in using the TWEAK and T-ACE screens, HRSA developed the "4Ps" screen ("Did your **p**arents/**p**artner drink, did you drink in **p**ast or during **p**regnancy?"). A positive response suggests referral. Since this questionnaire has not been validated, the ICC can either let it drop or assign researchers and evaluators to validate it. HRSA is interested in working with NIAAA to do so.
- C SAMHSA reported on several projects. Their assistance to children of alcoholics in San Francisco will soon include screening and follow-up for FAS. The Betty Ford Center is offering a full-day informational program for children of alcoholic parents. This information will be of interest to the ICCFAS.
- C DOJ has established a Juvenile Justice Workgroup, with 3 priorities: 1) collecting prevalence/incidence data in the juvenile justice population and report those data to legislators/other policy makers; 2) developing training programs for Justice

professionals; and 3) identifying/developing a model system for screening/providing early intervention services for youth in the Juvenile Justice system. These will be tested and replicated. The ICCFAS will fund this and further recommendations on subsequent action depends on the resources available.

- C The ICCFAS strategic plan for FAS was developed by the ICC organizations. They pledged to do the activities possible with funding from 2001-2005, but that was before 9/11. Nonetheless, most agencies are either ahead of what they promised, or are behind but working on it.
- C The next ICCFAS meeting will analyze what recommendations are coming to government agencies from various bodies (e.g., from CSAP on the town meetings; this Task Force; the Teratology Society, etc.). Those recommendations include one profile, two sets of curricula, three sets of agendas, two definitions, two endorsements, a checklist, etc.
- C The meeting planned for October was cancelled since the field is so small that most experts were at this meeting. Instead, an internal meeting will most likely occur in the first two weeks in December to review all these recommendations, determine who does what and how these activities follow along with the ICCFAS strategic plan, funding sources, etc. The Task Force members were all invited to attend the next meeting, although the NIAAA cannot pay for that travel.

National Task Force/CDC

Dr. Floyd reported on CDC activity in the past six months.

- C An article by Jasjeet Sidhu, was published in an April 2002 MMWR reporting on alcohol exposures and outcomes. The report found that one in seven pregnant women still drink, and 3% of those are binge drinking. Another MMWR article, published in May 2002, by Karen Hymbaugh reported the first FAS prevalence rates from the FASSNet (FAS Surveillance Network) states. In the 4 states monitored, 1.4% of children were born with FAS. These articles can be found on the CDC MMWR Web page: <http://www.cdc.gov/mmwr/>. FASSNet's methodology was also published in Teratology (2002, Vol 66).
- C Project Choices, a preconceptual study of behavioral interventions for women to prevent alcohol-related pregnancy outcomes, will publish a report in the American Journal of Preventive Medicine. It reports findings from an epidemiologic survey of 6 targeted settings including alcohol treatment, jail, primary care, OB/Gyn clinic in a university, and a media recruited group. The study, in looking for women at high risk for alcohol-exposed pregnancy, found that those settings concentrate women at high risk, making them important behavioral intervention targets.
- C *Pediatrics* also accepted publication of an article on the Project Choices pilot intervention. Three months post-intervention, 68% of the women were no longer at risk for an alcohol-exposed pregnancy. The efficacy trial is now underway and will be reported at the next Task Force meeting.
- C CDC's FAS recommendations were developed and distributed on the last day of the NCBDDD national conference. They will also be disseminated to a 50,000-person mailing list. The report describes the Task Force and outlines their recommendations for the future related to clinical, epidemiologic, basic science, and

health services research; appropriate and available service provision for women at risk and to affected persons; and public awareness and education about prenatal alcohol use, FAS, and other prenatal alcohol-related conditions.

- C Updates: In 2001, NCBDDD received additional funding that supported several initiatives, including targeted media campaigns in three sites (UCLA, St. Louis, Iowa). St. Louis is ready to roll out their campaign in late October.
- C Funding also was received to establish screening/diagnostic criteria and to develop an RFA for four regional training centers. These will develop curricula based on the criteria and disseminate them. In addition, the centers will work to promote the inclusion of FAS on licensing exams for medical and allied health professionals. The initial project period is three years, and the centers will disseminate other evidence-based products as well.
- C A cooperative agreement with South Africa will continue existing FAS surveillance and prevention activities with investigators there.

New Business

Meeting agendas. Dr. Riley expects that an e-mail vote will be required on whether want to develop a consensus statement to endorse grass roots programs or agencies now conducting FAS activity. Since that was too complex to address in the remaining 20 minutes of the meeting, he suggested that the next meeting agenda allocate time to review the action item status and discuss potential recommendations, keeping the informational aspect of the meeting at a minimum. That was agreed upon by the group, along with the following:

- C Conduct new business first, when energy is still high.
- C Utilize time between meetings, which requires the members' response to e-mails.
- C NCBDDD was asked to send the important informational materials electronically before the meeting so that most of the agenda could focus on dialogue/discussion.
- C A brief meeting summary should be provided in addition to the longer minutes.
- C NCBDDD was asked, as able, to make the PowerPoint presentations into text documents and to distribute them.
- C Dr. Snider and Dr. Floyd, shortly after the meeting, will develop a list of recommendations that were officially endorsed, if any, and action items. That could be issued fairly quickly and followed later on by the minutes. The minutes could also be reorganized (e.g., with a bold font) to highlight the recommendations.

Meeting with the Surgeon General. Dr. Snider suggested that the Task Force request a meeting with the new Surgeon General, providing him with information in advance, in order to outline the magnitude of the problem of FAS and to ask him to raise the issue in his talks around the country. Dr. Riley asked those interested in participating in this meeting with the Surgeon General to let him know.

Dr. Ken Warren, who was involved in the Surgeon General's initial report on the risks of drinking during pregnancy, agreed to Dr. Riley's request that he draft an update to be circulated to the Task Force for their comments. Dr. Warren provided some background on the advisory. Since the first advisory was issued in 1977, much more

information and research has been produced. The NIAAA reports are issued as the Secretary's reports. After the 1977 report, the FDA Commissioner asked for the authority to impose bottle labeling, a function under the domain of the BATF. The outcome of congressional hearings was to recommend a report by DHHS and the Treasury. Ultimately, they settled on a "wait and see" strategy, but they recommended that the Surgeon General issue another advisory. Dr. Warren drafted that report, which was approved by the Acting Surgeon General, and has been re-approved by every Secretary since. The advisory was a one-paragraph health recommendation, with an FDA recommendation at the end that the public should be aware of the alcohol content of food and prescriptions, accompanied by 1½ pages of findings. Since the statement is already in effect, perhaps attention could just be called to it by updating the science with the much stronger base of the past 22 years' work.

Closing Comments

Task Force Membership. Noting that some members' terms had expired, Dr. Riley asked them to not be concerned; more information will be forthcoming. He reminded the members that recommendations for new Task Force members are always welcome. A CV or resume should be forwarded to Ms. Jackie Vowell at NCBDDD. The next Task Force meeting is scheduled to be held on March 13-14, 2003. Then, with Dr. Riley's thanks to everyone for the cordial and productive discussions, the meeting adjourned at 12:40 p.m.

Minutes approved on 12/11/02
by Edward P. Riley, Ph.D.
Chair, National Task Force on FAS/FAE

Attachments: Subgroup Reports

Attachment 1: Screening and Diagnosis – ARND Subgroup Report

Initial Summary Recommendations from the Scientific Working Group on Diagnostic Guidelines for FAS and ARND

Co-chairs: Kenneth Warren, Claire Coles

Participants: Annie Acosta, Hani Atrash, Jacquelyn Bertrand, Herb Bishoff, Dan Dubovsky, Sheila Gahagan, Carole Lannon, Sarah McGovern, Luther Robinson

IDEA1. General premise: "Alcohol-Related Neurodevelopmental Disorder (ARND) is neurodevelopmental teratology that is caused by pre-natal alcohol exposure. It may be of varying degrees of severity. In a given individual, it may be difficult to differentiate neurodevelopment problems that arise from the alcohol exposure as distinct from other causes. Certain traits may vary with developmental age or stage. It is expected, though not definitive, that the types of neurodevelopmental deficits observed in FAS will be present in ARND.

Therefore FAS is a starting point for fully defining the nature of the deficits in ARND."

2. The topics of ARND and diagnostic guidelines relating to the disorder have not received the same attention as the full FAS diagnosis (most likely because of its later recognition and it is not always accompanied by facial or physical features). However, the panel did note children are encountered in medical, educational, and other settings who do not meet the criteria for full FAS, yet do demonstrate behavioral (broadly defined) problems.
3. It was the view of the subcommittee that a meeting of interested parties should be convened to discuss issues uniquely related to ARND, such as:
 - Barriers/challenges to describe this condition and how these barriers/challenges relate to those encountered in the full FAS diagnosis.
 - Additional professionals should be included (e.g., child psychiatrist, school psychologist) since these individuals are most likely to encounter the behaviors suggesting the need for assessment and/or referral, and these professionals have the depth of knowledge concerning behavior that may indicate ARND.
 - Behavior based guidelines and referrals should be developed for ARND, these guidelines will most likely related to full FAS.
4. Unique aspects of ARND that distinguish it from other developmental problems (e.g., ADHD, conduct disorder) need to be developed since these aspects may be particularly important for diagnosis and treatment plans for individuals should be developed
5. Aspects of ARND that can be confused with other disorders need to be clearly delineated for clinicians.

6. More neurodevelopmental data is needed to discriminate ARND from other disorders using evidence based methods.
7. Current nosology does not reflect common understanding of this disorder. (Most disorders/diseases are referred to by a single category, with exceptions noted [e.g., ADHD without hyperactivity] or with severity noted [e.g. mild, moderate, or severe mental retardation]). The issue of Fetal Alcohol Spectrum Disorder, and ARND as part of the spectrum – needs further delineation.
8. Prospective studies of children with prenatal exposure to alcohol are needed, urgently, to delineate the full range of ARND dysfunction, especially across exposure levels. Most current diagnostic studies have used data from clinic referred samples resulting in a bias picture toward children who are having problems and children more severely affected.
9. A wide range of studies from many sources, including international studies, are needed (further in accord with the item above). These studies will add to the knowledge base on ARND by:
 - Increasing the sample size of children with ARND to better delineate subtle effects,
 - Allow for investigation of the influence of parental and social environments and how these interact with the organic damage of ARND,
 - Allow CDC to address the global health impact of prenatal exposure to alcohol,
 - Allow for the investigation in ethnic variations in vulnerability to prenatal alcohol exposure.
10. Longitudinal studies of changes in development are needed, both:
 - Changes in manifestation of the disorder at different developmental stages, and
 - Changes in individual children with the disorder across the life span.

Attachment 2: Screening and Intervening in Prenatal Alcohol Use Subgroup Report

Co-chairs: Bob Sokol, Natalie Roche

Members: Jocelynn Cook, Dan Dubovsky, Tanya Sharpe, and Jasjeet Sidhu

Questions Addressed:

- C What are the *critical barriers* to primary care providers for screening for risk-drinking?
- C What *tools* are they using to screen?
- C What strategies for screening are working and not working?
- C What *information is needed* to increase screening?
- C What are the *critical components of a guideline* to assist primary care providers in screening?
- C What *information should be included in the guideline* regarding screening and intervening with pregnant women who drink alcohol?

Most discussion revolved around:

- C High-risk and low risk settings with examples of each
- C Appropriate prenatal screening tools, as endorsed by ACOG
- C Methods for determining when more in-depth screening procedures should be used
- C Options regarding interventions with a focus on brief and extended counseling interventions that can be administered by physicians or staff, such as brief talk therapy, computer-based teaching, and motivational interviewing.
- C A perceived need was to have systematic reviews of the selected interventions
- C Deliberations should be considered a first effort at delineating the essential elements of formal recommendations for primary care providers.

Recommendations of the workgroup were:

Settings (examples)

- Community-based organizations
- Community health centers
- Correctional facilities
- Drug or alcohol prevention treatment
- Family planning clinics
- Hospital ERs or urgent care centers
- Migrant health centers
- Prenatal clinics
- Sexually transmitted disease clinics
- Women's health clinics
- WIC clinics

Women

- Age >30
- Identified massed drinking, i.e., drinking on weekends, e.g., 4-5 drinks an evening on an average of once or twice per week